Episode: *Ethics Talk: Regret, Detransitioning, and Trans Health Services*

Guest: Kinnon MacKinnon, PhD, MSW
Host: Tim Hoff
Transcript: Cheryl Green

Access the podcast.

[mellow theme music]

[00:00:05] HOFF: Welcome to *Ethics Talk*, the *American Medical Association Journal of Ethics* podcast on ethics in health and health care. I'm your host, Tim Hoff. Trans health care faces an outsized share of scrutiny from some who are looking to undermine the validity of gender-affirming health services. Although regret can be experienced by anyone who receives health services and later feels dissatisfied with those services, regret is particularly politicized if it's expressed by trans people. One ethically relevant difference between patients' regret after transition-related surgeries and patients' regret after, for example, orthopedic elective surgeries, is that orthopedic patients' regret isn't typically used to suggest that no one should be allowed to have elective orthopedic surgery ever again. Ten percent of patients who received total knee arthroplasty, for example, are disappointed in the results, but few, if any, deploy this fact to bar all patients' access to knee replacements.

There are a few interesting and important follow-up questions we need to ask to more fully understand what's going on when a trans patient experiences regret. First, what does regret even mean? Is it regret about a specific result, a surgical procedure or medical prescription, or something else, like how they were treated or how their recovery process proceeded? Is it perhaps a combination of some or all of these reasons?

A key point here is that a trans person can experience regret about a specific thing but still want to draw on clinical expertise to affirm their gender identity in different ways. Just as a man might regret taking sildenafil citrate but not regret self-identifying as a man, a trans person might regret having had top surgery, but not regret self-identifying as a trans man, and might continue a prescription elsewhere that helps him maintain that gender identity. An upshot here is that a trans person can experience regret about a health service, but it doesn't follow from that regret experience that this trans person will want to detransition, or in fact, that detransition requires a total reversal of all medical, surgical, and social transition.

DR KINNON MACKINNON: Historically, the term "regret" was applied in really heterogeneous ways.

HOFF: That was Dr Kinnon MacKinnon, an assistant professor in the School of Social Work at York University, whose current study is the largest to have ever examined detransition and regret, and the first attempt from the field of gender-affirming care in decades to track and collect data from patients experiencing regret since pursuing gender-affirming medical or surgical care. Dr MacKinnon joins us today to discuss what we know about regret experiences of patients following transition-related care and just as importantly, what we don't. Dr MacKinnon, thank you so much for being here. [music fades]

MACKINNON: Thanks for having me, Tim.

[00:03:06] HOFF: To get us started, our audience would likely benefit from some background. So, can you help us distinguish between medical and surgical gender-affirming care? And please help us clarify medical from surgical detransitioning.

MACKINNON: Yeah. Thanks so much for having me and for the opportunity to speak to this topic. I would refer to this field generally as transgender medicine or transition-related medical care, in the sense that one who pursues these interventions are usually seeking to either masculinize or feminize their sex characteristics based on their assigned sex or gender. So in terms of medical intervention, someone who is transmasculine or assigned female at birth may pursue testosterone to masculinize their body, and someone who is transfeminine or assigned male at birth may pursue testosterone blockers as well as estrogen to feminize their body. And the surgical treatments that would be available would be, so for transmasculine people, chest masculinization, double mastectomy, lower surgeries, including gonadectomy, metoidioplasty, phalloplasty. And then for trans women or transfeminine people would be, some may pursue breast augmentation or orchiectomy or vaginoplasty.

[00:04:45] And most people, the majority, do not pursue any sort of detransition procedures. The best estimates are somewhere between one and ten percent may pursue medical or surgical detransition procedures, but those who do, this could involve simply stopping hormonal treatments. If someone's had a gonadectomy or lower surgery, it may require switching hormonal treatments. So, for example, if someone is assigned female at birth, and they're returning to a female or a feminine identity, they may have to take estrogen if they basically had an oophorectomy. And then some of the surgical procedures could be reconstruction. So, breast reconstruction after top surgery or chest masculinization, or for someone who is transfeminine, perhaps removal of breast implants, or potentially surgery for gynecomastia. So, if there was breast growth from estrogen, someone may want to have that reversed, the breast tissue removed. And very rarely would someone pursue a phalloplasty after vaginoplasty, but there are some individuals who do pursue that surgical procedure.

[00:06:27] HOFF: Hmm. And do we have—and we can get more into this later—do we have good numbers on the rates of people experiencing regret, as opposed to the rates of people pursuing some kind of detransition? Are those separately studied phenomena?

MACKINNON: Yeah, that is a, that's the million-dollar question. I would say that at the present moment, we don't have great estimates as to the prevalence of regret following transition-related surgeries. And that is primarily due to the way that studies are designed. So, we do have some data that would suggest that an experience of feeling that one regrets their prior medical or surgical care and starts to do a reversal process, that seems to occur in timelines between four and eight-and-a-half years, and we don't have many studies that look at collecting data at that sort of very long-term outcome. So it's just a bit difficult to say very precisely the estimates. In terms of patients actually pursuing a reversal procedure, there are some, you know, there's some evidence. There's one study that I can think of that would put that at less than one percent of people who previously accessed a transition-related surgery.

[00:08:05] HOFF: Mm-hmm. I have one final groundwork question before we move on. What does regret even mean?

MACKINNON: Mm.

HOFF: [chuckles] And by that, I mean how is it defined by researchers in this space? As we noted in the introduction to this conversation, regret can mean different things to different people. It can be a regret about a particular outcome, about a complication that arose during care. It can be regret about how the health care experience went, you know, how you were treated by health care professionals. It can be some combination of these, or in fact, something else. So, are researchers using similar definitions of regret or at least approaching some kind of common ground on a definition here?

MACKINNON: Yeah, that's a really important question. And the answer is largely no, not at the moment, or not within the body of literature. So, historically, the term "regret" was applied in really heterogeneous ways. So, regret could have referred to basically pursuing administrative changes, so legally reversing, returning to a legal gender status that was aligned with the assigned gender at birth. Or it could've referred to a feeling that one made the wrong decision or had kind of a change in their identity.

So, I'll give you one example. This is probably one of the most frequently referenced studies on regret. It's by Dhejne et al., and it was published in 2014. It looked at total Swedish population looking at prevalence of seeking transition-related care and prevalence of regret. It was a retrospective study using administrative data. And this study estimated that over decades, the average rate of regret was 2.2 percent. But the study didn't actually collect any data on feelings of satisfaction or dissatisfaction from the total number of participants who were included in the study. Rather, the 2.2 percent figure of regret was derived from individuals who actually applied to legally reverse their gender marker.

[00:10:40] So, different studies apply different definitions. There is one scale, the Decision Regret Scale, which is used more broadly in health care decision making, and this scale is starting to be used by some researchers in this field. So that would more specifically look at individuals who feel that they didn't make, you know, that they wished that they would've made a different decision, different health care decision, in the past. So we're, in my current study, which is examining individuals who've detransitioned and/or experienced regret, we are applying that measure, and I know of a number of other researchers who are beginning to use this measure.

[00:11:26] HOFF: Mm-hmm. So, looking at proxies for regret, like these administrative reversal requests in the Swedish study you were just talking about, that can be useful, but it can also be misleading. It's possible that a trans person, for example, might want to detransition in some ways due to their changing self-gender conception, but not necessarily experience what we would call regret. There seems to be a tendency in this conversation to conflate this desire to detransition in some ways with a very particular, narrow definition of regret about having pursued gender-affirming care in the first place. So which distinctions do you see as important for motivating clarity on this point?

[00:12:06] MACKINNON: Mm-hmm. Yeah. I mean, I think so much has changed in the field of transition-related medical and surgical care over the last couple of decades. So, I think we're learning a lot from gender diverse young people in particular who are driving some of the changes in thinking about gender diversity. So I think it's important to distinguish essentially shifts in gender identity that occur following an initial gender transition with hormonal treatments versus surgical treatments. Because we do tend to see higher detransition and identity shifts that occur following hormonal treatments, so that the prevalence of detransition following hormonal treatments is between two and ten percent. So that, and with detransition following surgical interventions, the prevalence seems to be lower.

But I think it's important to understand that I think that historically, when trans people started pursuing a medical transition, there was a lot of essentially coercion or encouragement or even requirement from the medical system to go through a full surgical transition. And this was required. So, for instance, in order to change one's legal gender marker, sterilization was required. So, going through with genital surgery and gonadectomy, this was a requirement from the medical system and the legal system for many, many years in most countries. So today, because of the advancements around trans activism and a move towards a more individualized approach to transition-related care, there isn't as much of external pressures for trans people to pursue surgeries. So, by that token, we may see less regret in that respect.

[00:14:35] HOFF: You mentioned detransitioning following starting hormone transition is about two and ten percent. Do we know how much of that is because of regret about the experience of taking hormone replacement therapies versus how much is due to, for example, having access to medications limited and then being essentially forced to detransition? Is that a distinction that's drawn in the data?

MACKINNON: Yeah, that's a great question. That's a great question. So, detransitioning can be prompted by multidimensional factors. And actually, many people who detransition usually cite more than one factor. So it's often a confluence of an identity shift, medical or surgical complications, mental health-related concerns. So, for instance, some people experience a decline in mental health through transition. And we all, sometimes gender minority stressors, so difficulty with being perceived as the gender that you are transitioning to, which renders one more vulnerable to, say, employment discrimination or interpersonal discrimination. And so, those factors often collide to bring someone to make this decision to detransition.

I would say that, again, the research is rather limited because very few researchers study detransition and regret. I would say that from the data that we do have, regret and detransition do often overlap. So, studies on detransition that have actually collected data on regret—because they don't always. So some studies on detransition actually don't even collect any data on regret—but the studies that do, they find that between a third to 60 percent of individuals who are detransitioning do report strong regret over their past medical or surgical treatments.

[00:16:39] HOFF: Hmm, mm-hmm. So let's talk a little bit about how we ought to respond to these regret experiences. As we went over in the introduction, the regret experiences of trans patients who have received transition-related care are used, or maybe I should say, misused, to argue that that type of care should not be available to anyone. This is in contrast to, as we've explained already, the regret experiences of patients who undergo, for example, elective shoulder

surgery. Those kinds of experiences are not really held against anyone in the same way. Nobody's arguing that there should be no elective shoulder surgery because a few people have experienced regret following it. So the one question we should pull out of this observation is this: Which criteria should we use to determine when, if ever, individual patients' regret experiences should be used to deny services to an entire group of similarly situated patients?

MACKINNON: Mm-hmm. Yeah. That's a really important and also complex question that you're raising there. So, I would push back on the framing a bit. I would first say that yes, I emphatically agree with you that feeling regret over a medical decision by a minority should certainly not be a reason to withhold or restrict treatment. But I think it's also important to parse out what we know from the evidence pertaining to adult transition-related care versus the quality of the evidence for pediatric transition-related care.

So, the debates occurring especially around pediatric transition-related care, I mean, regret does factor in there to some extent in the discourse, but more so the debates are about the risk-to-benefit ratio. So, medical ethics, the uncertainty in terms of long-term physical health outcomes, and also whether the treatments are effective in treating gender dysphoria with certainty and how that relates to the known and unknown risks in terms of long-term physical health outcomes. And so, there's certainly a lot of debate and discussion happening right now, and especially the political context does not make this any easier. But this is a pretty novel kind of emerging area of medical research around pediatric transition-related care. It's really only been scaled up in the last ten to 15 years in Canada and the United States. Ideally, we would have, at this point, higher quality longitudinal studies at this moment in time. And I think even now, conducting these, this research is just getting increasingly challenging.

[00:19:34] So, I think there's a couple of reasons why comparisons between transition regret and knee surgery or shoulder surgery kind of are tricky. And it's a little bit because of what I was talking about earlier in the way that regret's been kind of conceptualized and studied in divergent ways. So, transition regret in trans medicine can refer to a whole host of things, whereas in other surgical specialties we're usually referring to a desire for having made a different medical, you know, a different technique, different surgical technique, or dissatisfaction with some of the outcomes. But it's rarely looking at a complete reversal of, you know, it's not, you're not really examining, for instance, people that are pursuing a knee surgery reversal. They're also different in the sense of transition-related care is so intertwined with trans identity as well as trans people's civil rights in a way that's just not the case for, say, shoulder surgery.

Transition regret, I guess I'll more specifically talk about detransition, we're talking about an emerging experience around medical harm, arguably treatment failure, in some cases, really serious medical complications sometimes, from genital surgeries. And especially we're talking about a highly vulnerable group of patients. There's very high burden of neurodivergence, mental health challenges, age, if we're talking about children or adolescents. So, I think it's a little bit more complicated in that sense. Yeah.

[00:21:32] So, and I think the other point here is, so, in the last ten years, via media and social media, I would say we've kind of broadly promoted these medical interventions, in some cases, it's kind of like the path to happiness, community, complete body acceptance. And this has been accomplished in some ways through trans influencers. And so, what we're starting to see is a

group of some young people who have felt let down that the treatment didn't live up to its promises of happiness and self-acceptance. And that's quite different from the way that other surgical specialties operate. So I think that we, at this moment, at least—because I have personally been in this field for over a decade—I would say that in the early days when there was a lot of advocacy around treatments, so pushing for greater availability of transition-related treatments, I think that the...we're learning a little bit more today about some of these longer-term outcomes that were perhaps unexpected at the time. And I think we have an ethical responsibility to study and understand this particular emerging group of people's experiences.

[00:23:10] HOFF: Regardless of essentially this whole conversation, people experiencing regret following transition-related surgeries are still patients who need support. So, which best practices should health professionals follow to support patients interested in gender-affirming surgical care or detransitioning?

MACKINNON: Yeah, I mean, the first thing I would say is I hope that more researchers and clinicians are aiming to study and understand these experiences because I think they are really important, and we have a lot to learn. Certainly some of that research is happening. Many PhD students around the world are now actually tackling detransition as part of their dissertation topics. I think listening to detransitioning patients, not making assumptions, many of the same principles that would apply in terms of working with trans and LGBTQ patients would apply here. Most people who are detransitioning are also somewhere on the LGBTQ+ spectrum. So, following an affirming approach to sexual diversity, gender diversity is really important. I would say to take a pretty neutral approach, at least to start, to get an understanding of an individual's experience.

Some of the people who are detransitioning sometimes have not the best interactions with gender-affirming care providers, because I think sometimes, they are presented as being double trans or like extra trans because they are having this second transition. And for someone who's experiencing profound regret, that can feel insensitive to their experiences. or maybe trying to put a positive spin when someone's experiencing regret is not always, it may backfire. It may not be the right approach. So just being open, how to explore how someone feels about their initial transition and what do they need going forward? Do they need psychosocial supports? Do they need peer supports? Community supports? Are they interested in pursuing any sorts of reversal or reconstruction, or are there surgical complications that need to be addressed? [theme music returns] So, some of that would be really helpful when encountering a patient who's detransitioning.

[00:25:57] HOFF: Dr MacKinnon, thank you so much for your time on the podcast today, and thank you for all the work you do into this important topic.

MACKINNON: Thanks so much, Tim.

HOFF: That's all for this episode of *Ethics Talk*. Thanks to Dr MacKinnon for joining us. Music, as always, was by the Blue Dot Sessions. To read this month's issue on Regret in the Moral Psychology of Surgical Professionalism for free, visit our site, journalofethics.org. Follow us on X @journalofethics for all of our latest news and updates. And we'll be back next month with an episode on Surgical Care for Incarcerated Patients. Talk to you then.